

## Fatherhood: experiences of fathers of boys diagnosed with Duchenne Muscular Dystrophy

Silvana Aparecida de Lucca<sup>1</sup>  
Eucia Beatriz Lopes Petean<sup>1</sup>

**Abstract** *This study's aim was to understand the experience of being the father of a boy diagnosed with Duchenne Muscular Dystrophy (DMD). Eight fathers of 10-year-old or older boys diagnosed with DMD, living in Ribeirão Preto and surrounding cities participated in the study. Interviews included a semi-structured script and data were analyzed according to thematic content analysis. The results show that the confirmation of a DMD diagnosis shocked fathers and was mixed with sorrow, helplessness and hopelessness. Most fathers considered the illness of their child to be a mission sent by God, which helps to alleviate the pain and anguish caused by the disease. As the symptoms started manifesting, the fathers experienced losses that exposed them to great suffering and triggered an anticipatory mourning process. The fathers assigned to the disease the meaning of a mission to be accomplished and considered themselves to be "special fathers", which positively influenced their adaptation to the disease. Identifying and understanding how fathers experience fatherhood in the presence of a chronic disease/disability is essential to devising psychological counseling and care programs directed to fathers and their families.*

**Key words** *Fatherhood, Duchenne Muscular Dystrophy, Chronic disease, Mourning*

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<sup>1</sup>Faculdade de Filosofia, Ciências e Letras de Ribeirão Preto, USP. Av. Bandeirantes 3900, Vila Monte Alegre. 14040-901 Ribeirão Preto SP - Brasil. silvana.lucca@gmail.com

## Introduction

In our culture, getting married and having children are considered part of the development of human beings and have an enlarged social and psychological meaning. Thus, becoming a father/mother is a stage that brings with it significant changes both for the family as a whole and its members individually, changing the family dynamics and requiring its members to adapt to a new context, changing roles and existing relationships and affective bonds<sup>1-3</sup>. Becoming a father, as well as becoming a mother, is the most challenging moment of the family or individual life cycle<sup>4</sup>.

According to Krob et al.<sup>5</sup>, men experience the pregnancy with intense feelings of joy, anxiety, conflict, and concerns regarding the mother's and the baby's health, experience feelings of exclusion both before and after delivery, and hold expectations regarding their role, about being participatory fathers and being present in the lives of their children.

Teykal<sup>6</sup> emphasizes that becoming a father involves two dimensions of an individual's identity: the physical dimension, as men participate in the child's conception; and the moral dimension, which demands resources to support and raise the children. In the role that has been traditionally disseminated in contemporary societies, the father assumes the role of provider and the mother of caregiver. According to Darling et al.<sup>7</sup>, fathers have been pressured to assume greater responsibilities regarding the care provided to their children and household chores. Levandowski and Piccinini<sup>8</sup> assert that fathers are seeking to be more present and participatory, breaking from the maternal monopoly over children. Feeling that one is a father, however, does not depend only on having the certainty that the mother-to-be is pregnant, as happens with maternity, rather it is a feeling that develops in the relationship between father and child, which is often intermediated by the relationship the father establishes with the mother<sup>9</sup>.

Fonseca<sup>10</sup> states that "while mothers want babies, men want a family", clearly showing cultural differences. The literature shows the importance of the father's involvement to the family's development and proper functioning because adaptation to this new phase depends on the complementary roles performed by both parents<sup>11</sup>.

There may be, however, complicating elements concerning motherhood and fatherhood. Parents of individuals with chronic diseases, disabilities, or other unpredictable conditions face additional difficulties. The family has to acknowledge the

disease's diagnosis and prognosis, often laden with hopelessness and misinformation<sup>12</sup>. A moment that is supposed to be special becomes a traumatizing and destabilizing event and, similar to what happens with mothers, the image of the ideal child is dismantled, shaking fathers and interfering in the conception they hold of fatherhood<sup>2,13</sup>. The prognosis forces parents to acknowledge the possibility of death, not only the physical death of a family member, but subjective deaths, that is, the death of the expected/idealized child, of expectations of normal child development, which trigger an anticipatory mourning process<sup>14,15</sup>.

The literature<sup>16-21</sup> shows that most studies addressing the family in the context of disabilities usually focus on the mother and the maternal figure, while few studies address the father figure. Whenever fathers appear, they appear together with the maternal figure, so that the term "parents", rather than "fathers", is used as the main theme and objective of many studies.

Even though the number of studies addressing fatherhood has increased in recent years, Cunniff<sup>22</sup> stresses that few studies focus on the adjustment of fathers when the child presents a disability or a chronic disease, especially Duchenne Muscular Dystrophy (DMD).

DMD is a chronic degenerative disease that affects male children and manifests at an early age. It is a genetically determined disorder in which the affected gene is recessive and X-linked, causing problems in the encoding dystrophin, the protein responsible for the maintenance of muscle cells, affecting approximately one in every 3,500 boys<sup>23</sup>. The boys are born healthy, start developing as any other child, but then, usually at the beginning of the second decade of life, numerous functional losses take place, muscle weakness progresses, the individual loses the ability to walk, becomes confined to a wheelchair, and then dies around the age of 20 years old due to cardiorespiratory complications, because the muscles of these systems are also affected. Up to the present, there is no cure for DMD. The entire family suffers and needs to learn to deal with the responses and feelings the disease arouses, the presence of which interferes in one's fatherhood and motherhood.

## Method

The objective of this exploratory, descriptive study of a qualitative nature was to identify the experience of being the father of a child with

Duchenne Muscular Dystrophy (DMD). Eight fathers of 10-year-old or older boys diagnosed with DMD for at least two years participated in the study. These criteria were used to ensure the fathers had a long experience with the disease. A convenience sample was used and the participants were approached at the Association of Muscular Dystrophy in Ribeirão Preto and at the Outpatient Clinic of Child Neurology at HCFMRP, Ribeirão Preto, SP, Brazil, where these children received treatment. Due to the study's nature and the fact it is based on a rare disease and addresses a small number of participants, the results cannot be generalized. Semi-structured interviews were used including themes that encouraged the participants to verbalize their ways of thinking or acting regarding the pregnancy, fatherhood, the diagnosis, changes perceived after the diagnosis, and the child's care routine.

The interviews were held in the participants' homes, recorded and later transcribed verbatim, seeking maximum precision and reliability in regard to content. Data were analyzed using content analysis<sup>24,25</sup> and the psychodynamic theory was the framework used to interpret and understand data<sup>26</sup>.

The transcribed material enabled immersion into the testimonies of these fathers, to seek meanings and subjective significations that spontaneously emerged in their reports following the phases proposed for this method: pre-analysis, exploration of material, and analysis<sup>24,25</sup>. The analysis was guided by the following categories: Fatherhood, Diagnosis, Meaning Assigned to the Disease, and Mourning. This study was approved by the Institutional Review Board at *Hospital das Clínicas* at FMRP/USP.

## Results and discussion

The fathers' ages ranged from 35 to 65 years old; salaries were between 3 and 10 times the minimum wage, current at the time of the study; and for most (seven), the fathers' job was the family's only source of income. In regard to number of children, seven participants had two children, while two of these participants had both children with DMD; one father had four children; and all participants were married.

### Fatherhood

The fathers addressed in this study reported satisfaction with fatherhood and with the fact

they were following life's "natural course". *I've always wanted, you know, to follow the natural order of things, I've always wanted to have kids* (P3). According to Krob et al.<sup>5</sup>, even when fatherhood is not planned, fathers experience satisfaction and pleasure with the fact they are becoming fathers.

For these participants, becoming a father has an identity function, *A man turns into a man when he becomes a father* (P3), and fatherhood has a social function with a well-defined role. *The first thing is to support your home, right?... the father is the one who is supposed to work the most with the family, he has to be ... the family's model* (P4).

The reports emphasized how significant fatherhood is for these fathers who perceive it to be inherent to their role that of providing for the family, promoting education and training in various dimensions, from formal education to spiritual orientation, and actively participating in relationships and at home. These results are in agreement with the studies conducted by Brasileiro et al.<sup>27</sup> and Krob et al.<sup>5</sup>.

The parents' conceptions regarding fatherhood show that, for some of them, transition to fatherhood, becoming a father, was a time in which they re-developed their masculine identity, a fact presented by Teykal<sup>6</sup>. The fathers felt more gratified and had a sense they were helping the family to adapt to the disease when they took part in the care provided to the child and were more present in the family's life, feeling guilty whenever were not able to play what they consider to be the father's role. Directly participating in the child's care and sharing household chores are reported by the fathers who took part in this study. These participants exhibited less traditional fatherhood with a pattern admittedly more participatory and affective, revealing a model of fatherhood that seeks dialogue and responsibility, which is far from the idea of an authoritarian father as described by Ceverny and Chaves<sup>28</sup> and Levandowski and Piccinini<sup>8</sup>. The provider role is very important, but does not ensure satisfaction with fatherhood; limited availability to take part in family life was negatively related to the desired state of fatherhood, leading to frustration and feelings of guilt among the fathers addressed in this study. Henn and Piccinini<sup>29</sup> and Teykal<sup>6</sup> note that men feel frustrated and guilty when they were unable to play the ideal father's role to which they aspired for themselves.

Being the father of a "special" child was considered to be an opportunity for personal growth and they felt they were chosen by God to be "special fathers", ... *I guess I was chosen, I have a role to play for a special someone, ... It makes you grow*

a lot... (P1). They consider fatherhood itself an opportunity of personal growth. They report they became more responsible and more mature after the experience of becoming a father. Similar results were also reported in the study conducted by Lemayet al.<sup>30</sup>

Being the father of a child with a rare disability positively impacted the fathers' personal development, as portrayed by Povee et al.<sup>31</sup>, who studied the functioning of families with children with Down Syndrome.

The fathers addressed in this study talked about the importance of staying strong in the face of adversity and providing good examples to their families; even though they may falter at times, such a fact should never be revealed to the family. These fathers challenged the social imagery of strength and vigor attributed to men: *I've never shown weakness to them, I never... you know, sometimes, I cried... I never spoke of it... I've always supported them* (P4). This reveals they require themselves to be able to face all challenges without escaping from fighting, typifying the behavior expected from the male gender, as described by Bruschini and Ricoldi<sup>32</sup> and Nolasko<sup>33</sup>. The idea of not being able to show weakness in the face of difficulties refers to usual roles assigned to genders and to the patriarchal father figure and Latin male stereotype<sup>33-35</sup>. We must, however, consider the harm caused to men when they conform to these attributions: not allowing themselves to show weakness, or their feelings, or not having a close relationship with their children.

### Diagnosis

Some reported that the search for a medical diagnosis started after they perceived differences in the development of their children compared to other children or when some clear signs appeared such as an enlarged calf or when motor problems worsened: *when he turned four, his calf started to get bigger and we also realized that younger children were able to climb a chair but he didn't, he'd fall easily and we started getting concerned* (P4).

The "delay" and long time that passed between the onset of symptoms and diagnosis, combined with various exams the child has to take, generate anxiety, anguish, and uncertainty both in fathers and mothers, who yearn for answers. Moreira and Araújo<sup>36</sup> and Petean<sup>2</sup> indicate the need for a diagnosis, and consequently related information, to be provided as quickly as possible in order to attenuate anxiety generated by long waits.

When development does not follow the expected pattern – as is the case of a rare disability with limited life expectancy – a mourning process is triggered among fathers in the same way that happens to mothers. They experience anguish and uncertainty about the future of their child and of themselves. According to Goes<sup>37</sup> and Krob et al.<sup>5</sup>, the disability of a child elicits psychological problems in both fathers and mothers because they cannot find traces of the ideal child in their real child, which hinders the identification process. The fathers in this study had already seen the real child, but both the disease and the perception that their children presented a development pattern different from what is expected, ultimately leading them to experience the loss of their expected child.

The reports show that some fathers did not feel sufficiently clear about the diagnosis, as happens with mothers and families<sup>2,13,14,38</sup>. Various feelings emerged at the time the diagnosis was disclosed, hindering understanding and assimilation of medical information. The fathers were unclear about the moment when the diagnosis was disclosed, *I guess the doctor also said* (P2) and revealed that some time is required to assimilate information, suggesting psychological defenses can emerge. Various studies<sup>2,39-44</sup> show that parents experience intense feelings that interfere in the way they understand information when receiving a diagnosis of chronic disease for their child.

The way the diagnosis was reported and the point in time at which it was reported was recalled by the fathers who were present at the consultation together with the mothers as a painful moment, [...] *I guess your child has a disease, [...] sounded like a bomb [...] we were talking about muscular dystrophy and the person would open a book and then close it.* (P1).

With the objective to sensitize parents about the severity of the disease, health professionals base their posture on scientific knowledge, seeking to reinforce the chronic and lethal nature of DMD, for fear that religious values and beliefs lead parents to expect an illusory cure: *There's no help in making promises [to the saints], you understand? There is no use taking him to a spiritual healer; it won't solve the problem, you understand? Not even in Aparecida, it won't solve the problem* (P1). [T.N. Aparecida is a city in the interior of São Paulo, Brazil where the image of Our Lady of Aparecida was found by fishermen and to which miracles were attributed. It is currently the largest peregrination center in Latin Ameri-

ca.]. A discussion about how to proceed during the difficult time of disclosing such a diagnosis is relevant since religiosity is one of the few sources of hope and support available to parents in a time like this. The way the diagnosis is disclosed interferes in one's ability to accept or reject the child and in the family's ability to adapt to the disease, so that measures need to be implemented to humanize health services and improve the knowledge of healthcare workers regarding potential responses and defense mechanisms that take place in moments like these<sup>38,40,44</sup>.

The shock the fathers experienced at the time of the diagnosis was reported with expressions of great suffering, accompanied by feelings of helplessness and confusion. *It was a shock when we went to São Paulo...when we got the news he had dystrophy... it was very shocking* (P3).

Verbalizations among the fathers addressed in this study more frequently referred to the shock they experienced, similar to what was observed in the study conducted by Petean<sup>2</sup> in which mothers were addressed, and in the studies conducted by Camargo and Londero<sup>40</sup> and Poysky and Kinnett<sup>41</sup> and Cavalcante<sup>38</sup> in which families participated, showing that the fathers' responses are similar to those of mothers. Others responses may be associated with surprise, doubt, denial and anger. Kluber-Ross<sup>45</sup> describes the shock one experiences when receiving the news of a severe disease or when facing significant loss as being a temporary response that gives way to other defense strategies later on. This response is related to the content of the news, in this case the diagnosis, but it is also related to the way the diagnosis is disclosed.

It is likely that the painful experience at the time of the diagnosis triggers a defense process such as denial and parents believe that the child can get better so they seek miraculous treatments and, ultimately, a cure. These processes, denial and search for a cure, experienced by fathers, do not differ from those experienced by mothers as shown in the literature<sup>2,14,44</sup>. In this sense, Camargo and Londero<sup>40</sup> state that when fathers try to improve the child's health condition without having received proper guidance, or without having fully understood all information, they end up making decisions that may harm the child's condition instead of improving it.

The disclosure of a child's disability, chronic disease or other condition that interferes in a healthy development requires clarification and that accurate information be provided in language accessible to parents so they are able to

assimilate the information and mourn for the loss of their ideal child<sup>38-43</sup>. In the face of the pain caused by the confirmation of a DMD diagnosis, the fathers addressed in this study became astonished, unable to act at all because, according to their perception, the news was provided in abrupt way.

Hopelessness, helplessness, and desperation were also reported, as well as a desire to die. In the face of the diagnosis of an incurable chronic disease, these are expected responses and have been described by studies<sup>2,14</sup> conducted with mothers, showing that both fathers and mothers suffer and react in the same way in the face of a diagnosis of disability or chronic disease.

When asked about the future, the fathers talked a little about their children's life expectancy, showing difficulty in dealing with the prediction of death inherent to this diagnosis. They felt emotional and confused when talking about the subject. *What I face with Renato is not a problem at all, whatever there is to happen, will happen and that's it. What I know [pause]... it's hard to talk [crying]* (P7). Parents of children with degenerative diseases with a prognosis of death anticipate the mourning process<sup>14,15</sup>, a situation that impedes their expectations and dreams for their child's future.

### Meaning assigned to the disease

Despite scientific knowledge concerning the cause of DMD, the fathers felt the need to find a justification, a meaning for their child's disease, confronting and even questioning the scientific explanation provided.

*My opinion is that it was a genetic mutation; I don't think my wife has it. The other opinion is a religious opinion I have, that nothing happens by chance.* (P4)

For some fathers the disease acquired the meaning of a mission to be accomplished by them or the child himself, something designated by God.

*So I was chosen. [...] I can see God saying 'I'll give you this one for you to take care of.'* (P1)

The reports show that the meaning of the disease is permeated by the fathers' system of beliefs and values, and, in a special way, by their religiosity, which in this study acted as a facilitator or a protection factor, helping them to face the disease and daily routine. When they assigned the meaning of a mission to be accomplished, the fathers were not only able to assuage anger directed to God, but also to attenuate the notion that their

child's disease was imposed by God as a punishment. In this way, they reconciled with God, preserving His image as a protective and fair "Father" to whom they can turn in times of pain. When the impossibility of cure through scientific means is accepted, religiosity is the only source of hope for these fathers. Mothers also present beliefs and values that help them to signify the disease and use religion as a coping mechanism<sup>2,13,14</sup>. In the literature<sup>37,46</sup>, religion appears as an instrument that helps explain and give meaning to disease and death experiences, helping the family to accept, adapt and adjust to the condition.

### Mourning

The fathers' reports reveal the process of loss of the idealized son and his normal development, which begins when symptoms are perceived and the diagnosis and course of the disease is confirmed. Their expectations were *be a normal child, a child who could play ball, run, fool around. I've never imagined I'd have a son with a degenerative disease.* (P4)

The fathers in this study showed difficulty in dealing with the functional losses that took place in the course of the disease, especially when the child lost the ability to walk, *it's really ugly when they stop walking, my son started walking in a way, it's terrible, he'd fall, cracked his head, cut his chin, he'd hurt all over, they walk like a duck, he looked like a duck, you know?* (P5).

The fathers showed that they understood the course of the disease, were aware of the subsequent stages, functional and progressive losses that affect the children, and for this reason, they cannot verbalize about the future. They know what is coming and are aware they need to be prepared, but they avoid talking about the subject and wish they did not know. There is a conflict in the affective sphere because objective knowledge regarding the disease's prognosis and the need to talk about it bring them into contact with a reality they fear and do not want to see concretized. As put by Kluber-Ross<sup>45</sup>, the mourning process implies stages that do not process linearly. Even though their reports show they are coping and adapting to the reality of the disease, when they are asked about the future, denial reveals itself once more.

The impossibility of cure and the prognosis of progressive and lethal degeneration lead fathers to frustration and anguish, because the fathers acknowledge that they lack power to alleviate their child's condition, as there is

no possible treatment to restrain the course of the disease or the death of their child at such a young age. Pangalila et al.<sup>47</sup> conducted a study with the fathers of adults with DMD, showing that despite their excessive workload, they consider taking care of their children to be important and gratifying.

The diagnosis of a chronic or degenerative disease such as DMD triggers an anticipatory grieving process because parents, aware of the course of the disease, see their expectations of having a normal developing child fade. As Roland<sup>48</sup> stresses, at every moment the disease advances, its progressive and lethal course is confirmed. Families then face anticipatory suffering due to disabilities and imminent death. The anticipatory mourning process, initiated when functional losses are perceived, may last a long period. These losses lack elaboration, whether on the part of the patient or on the part of the family, and arouse a range of painful feelings in all those involved<sup>49</sup>. According to Kovacs<sup>50</sup>, a long mourning process entails physical and psychological weariness in parents.

It is painful for parents to consider the death of their child, which in this specific case comes slowly and inexorably. The fathers who participated in this study were aware of the stages concerning the progression of the disease, and knew that each involution confirms the imminence of death. It is a considerable rupture in the expected course of life, which presupposes that the death of parents will precede that of children<sup>49,51</sup>.

Some of them talked about death and reported they do not only fear the death of their child but that of themselves and that of mothers, *Seeing a child die, what mother can bear seeing her child dying little by little?* (P5)

The close bond established by these men with their children, given their great dependence on others, cause the fathers to feel that their lives and that of their wives will be meaningless after their children's death, as there is a great deal of physical, affective and financial investment to keep them alive. According to Cunha et al.<sup>52</sup>, the close relationship established between caregiver and patient strengthens bonds during the course of the disease. The caregiver perceives him/herself to be involved at increasing levels and responsible for promptly meeting the patient's needs in order to alleviate suffering and feelings of guilt/he may have toward the patient. Since most activities performed by parents involve the care provided to their child, thinking about his death also implies losing their caregiver role.

## Conclusions

This study's objective was to identify the experience of fathers of children diagnosed with Duchenne Muscular Dystrophy (DMD), and even though generalizations are not possible, the results show a number of things.

The way fathers respond to the situation is related to the meaning they assign to DMD, their preconceptions, and moral and religious values, and does not differ from the way mothers respond. Fathers experience the same feelings as mothers, but in a different way than women: their caregiver and provider roles overlap, often hindering the manifestation and elaboration of their feelings. Another difference in terms of gender is that men rarely expose their feelings. The parents of a child with this condition experience an anticipatory mourning process that worsens

with physical and emotional overload accruing from the child's condition.

Being the father of a child with disabilities made them feel like "special fathers" promoting maturity and personal growth and was considered a mission to be accomplished. This meaning was permeated by a system of religious beliefs and values similar to the experience of mothers, as shown in the literature<sup>2</sup>. Fathers suffer as much as mothers with the diagnosis of the disease and need social and professional support to deal with it.

This study's results provide important information and open up a path for new studies aiming to identify the implication of being the father of a child with a chronic disease and related psychosocial factors. It is essential to provide opportunities for fathers to share their experiences to help them explain losses and gains obtained in the course of degenerative chronic diseases.

## Collaborations

SA Lucca and EBL Petean participated equally in all stages of preparation of the article.

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